

Johns Hopkins faces further criticism over experiments

Deborah Josefson *San Francisco*

The Johns Hopkins University Medical Center, in Baltimore, Maryland, is facing fresh criticism over its research methods and ethics—this time in relation to a study of different ways of getting rid of lead paint in homes, during which children were knowingly exposed to high levels of lead.

The centre temporarily lost its licence for research on humans recently after a previously healthy woman died in an asthma study (28 July, p 186).

Now two families have won the right to pursue a court case against the Kennedy Krieger Institute, which is affiliated to the Johns Hopkins University Medical Center, claiming that in the study it allowed their children to

sustain lead poisoning and brain damage by failing to inform them that they lived in housing with dangerous levels of lead dust. The Kennedy Krieger Institute, located on the university's campus, is nationally recognised in the field of lead poisoning and childhood neurological disorders.

The study, which ran from 1993 to 1995, was conducted in 100 homes contaminated with lead paint. In Baltimore city more than 100 000 homes have lead paint and over 4000 children annually test positive for raised serum lead levels.

The aim of the study was to find a cheaper and less hazardous way of removing lead paint than stripping the paint off the walls. The work was funded

largely by a government grant.

Landlords were paid from \$1650 (£1178) to \$7000 to partially remove lead by scraping off peeling paint, to paint over existing paint, or to add coverings. Residents were allowed, and in some cases encouraged, to remain in their homes while these removal techniques were going on. Lead levels of children living in the homes were periodically tested to monitor the efficiency of the various techniques.

Maryland Court of Appeal ruled 7 to 1 to allow the lawsuit to move forward, using the occasion to tighten safety precautions in research involving children and to restrict such research further. They also criticised Johns Hopkins' institutional review board for allowing the study to proceed.

Judge Dale Cathell compared the Kennedy Krieger study to Nazi experiments on concentration camp victims and to the Tuskegee experiment, in which syphilis in black men with

the disease was allowed to progress (rather than be treated with penicillin) so that the natural course of syphilis infection could be studied.

The appeal court's indictment of the Kennedy Krieger study has also resulted in an investigation into the study by the Department of Health and Human Services' Office of Human Research Protections.

But Don Ryan, executive director of the Alliance to End Childhood Lead Poisoning, in an article in the *Baltimore Sun* newspaper (2001; 28 August) defended the lead research, saying: "The reality is that this research made homes safer, not only for the children in Baltimore but for hundreds of thousands of others across the nation. Children do not live in lead-burdened houses because researchers want to 'experiment' on them but because so much of our housing is contaminated by lead." □

AIDS expert challenges ethical stance on drug trials

Bryan Christie *Edinburgh*

Measures to protect people in developing countries from being exploited in medical research trials may prevent some projects going ahead that could improve the health of poor people, a leading scientist has warned.

Professor James Whitworth of the Medical Research Council's programme on AIDS in Uganda said it may not always be practical to test new treatments against the best treatment currently available anywhere in the world.

New ethical standards laid down in the revised Declaration of Helsinki last year stated that testing of drugs in developing countries should be done against the best current treatment and not against placebo. This was designed to ensure that local populations would benefit from trials by gaining access to the best current treatments.

But Professor Whitworth, speaking at the British Association's Festival of Science this week in Glasgow, said this might prevent some ethical and

necessary research from going ahead.

"The central problem is trying to be as fair as possible in what is an unfair and unequal world," added Professor Whitworth. "Of course the same treatment should be available in Nairobi as New York, but it isn't and it isn't going to be. The medical problems of the developing world are immense and urgent. We can't wait for politicians to create global equity."

"It seems a strange sort of logic to stop doing trials in Africa that are trying to help improve the health of poor people so that people in rich countries can have peace of mind."

He also questioned the insistence that informed consent should be given in writing, when such a process may have little validity in some cultures.

"Getting a signature on a piece of paper is nice and can be easily checked but is actually no guarantee of informed consent. Properly witnessed verbal consent can be much more valid and relevant," he said. □

Woman passes first hurdle in right to die case

Zosia Kmietowicz *London*

The right of terminally ill patients for assistance to end their life moved a step closer last week when a woman with motor neurone disease won the battle to have her case reviewed in the high court.

Diane Pretty was diagnosed as having the disease in 1999. Now aged 42, she is paralysed from the neck down but is fully mentally competent. She wants to die at home when she chooses but is physically unable to take her own life.

On 31 August she won the right to a full judicial review of the director of public prosecution's refusal to guarantee that Mr Pretty would not be prosecuted under the 1961 Suicide Act if he helped to end his wife's life. Her case could be heard within the next month. Under section 2.1 of the act, Mr Pretty could be imprisoned for up to 14 years if he helped his wife to die.

Liberty, the human rights organisation that is representing the Pretties, and the Voluntary



Diane Pretty arriving at court with her husband, Brian

Euthanasia Society claim that because of the exceptional circumstances of the case Mr Pretty should be exempt from the Suicide Act.

At the moment the Netherlands and the state of Oregon in the USA are the only two places in the world that allow voluntary euthanasia. □